

## Addressing Grief and Loss in Individuals with Intellectual Disabilities

- ♥ ***Loss does not necessarily have to be death related.*** There are other loss situations which might be experienced by residents and individuals with intellectual disabilities. Staff turnover change in roommates, the end of weekly visits by a devoted parent - now dead - and the death of people one has lived with for many years.
- ♥ ***Help them identify what grief and death are.*** Many individuals with ID have been sheltered from death and may be confused by what it means. People often think that they are protecting the individuals by not telling them when actually more confusion is being created. Caregivers and loved ones sometimes avoid telling individuals about death due to fear of behavioral and emotional consequences. However, it is important to be honest and open with individuals. Listen to them and remember the many different feelings and actions that all people experience, regardless of age or ability, when grieving.
- ♥ ***Use simple, concrete language to describe death and grief.*** “Death means someone’s body and mind are gone, and they will not be coming back.” “Grief is when you are sad that someone you cared about died.” Avoid using clichés like “he passed away” or “she is just sleeping”. This can create more confusion and misunderstanding. Use language and words that the individual will understand. Use pictures and picture books to help explain if necessary. If possible, have someone they trust and care about tell them the news of a death.
- ♥ ***Be patient if they ask the same questions over and over again or don’t seem to fully grasp the idea of death.*** Some individuals may seem to understand death at one time and then not at another. They may ask when someone who has died is coming back. Make sure to emphasize in words they understand that death is final and not temporary, “She cannot come back because she is dead.”
- ♥ ***Discuss the different emotions all people feel when they have a loss.*** Being sad, angry, depressed, losing sleep, not eating, and being irritable can all be signs of grieving in all people regardless of age or ability. Reassure individuals that they are not alone and provide space or comfort when necessary or requested. Acknowledge their feelings by saying things like, “I know you are really sad right now because of your friend dying. I was sad when my friend died too” or “You’re really mad at your dad for dying. It must be really hard to feel that way.”
- ♥ ***Address the individual directly, irrespective of whoever is with them.*** If they have experienced bereavement say you understand how sad and painful this must be. Look into the loss history of individuals who have an intellectual disability and take into account other losses that may have resulted, such as moving home or losing contact with other significant people.

- ♥ ***People with intellectual disabilities may express difficult emotions through their behavior.*** Grief reactions may not necessarily be recent but can come about at any time and past losses could help explain current actions. For example, “You got upset today because you were missing your mom.” Again, remember how all of us react when we have these experiences.
- ♥ ***Be honest, include and involve.*** The person should be offered the choice of whether to attend the funeral or memorial service. If he or she is unable to choose directly because of cognitive limitations, it is usually advisable to involve the person as fully as possible in all the rituals being arranged.
- ♥ ***Listen - be there.*** Being available to listen and provide support is essential. This must occur immediately after the death, and, most importantly, also in the weeks and months following. Understanding the permanence of death comes slowly, thus the person with a developmental disability may experience delayed grief.
- ♥ ***Actively seek out nonverbal rituals.*** The nonverbal rituals with which most cultures surround death are helpful to many of us. They are particularly helpful to people with intellectual disabilities who cannot use written or spoken words. Counseling picture books may be helpful in explaining what happens when someone dies.
- ♥ ***Respect photos and other mementoes.*** In the early stages of a bereavement it is quite common to avoid pictures and possessions and places which are associated with the person who died. As time passes, such mementoes may come to be treasured. People with an intellectual disability should be helped to choose some mementoes, and this choice should be offered again at a later date when some of their emotional pain has subsided. Sometimes people make unexpected choices, but these should be respected. Say something like, “That shirt is important to you because your brother gave it to you.”
- ♥ ***Try to minimize changes in routine and changes in accommodation or of caregivers at a time of grief.*** As a rule of thumb, major changes should be avoided for at least one year.
- ♥ ***Some individuals may show searching behaviors in which they are looking for someone they have lost.*** By revisiting old haunts, caregivers can assist appropriate searching behavior to support emotional recovery. Hoarding behavior may suggest that more help of this kind is required. For example, the person who absconds or is found wandering may be trying to find their lost home and family. Some individuals may become slow and uncooperative with ordinary routines.
- ♥ ***Anniversaries should be formally observed if possible.*** Many religions have formal services a year after someone has died. This is especially helpful at the time of the anniversary of an

important loss. Individuals may want to make a calendar that marks dates that correspond with their grief and are important to them like a loved one's birthday or death day.

♥ **Things to Say**

- "I'm sorry your loved one died."
- "I am here for you."
- "I care about you"
- "I don't know how you feel, but I am here to help you."
- "I was very sad when my loved one died too."

♥ **Things NOT to say**

- "At least they lived a long life, many people die young."
- "S/he is in a better place."
- "S/he brought this on him/herself."
- "Aren't you over them yet? They have been dead a while now."

♥ **References**

University of Hertfordshire, 2016. *Managing Grief Better: People with Intellectual Disabilities*. <http://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities>

Hrepsime Gulbenkoglou, 2007. *Supporting People With Disabilities Coping with Grief and Loss: An easy-to-read booklet*.